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Lost in translation!
Palliative care in non-malignant disease?

George Kernohan, *Professor of Health Research*; **Mary Waldron**, *Researcher*; **Felicity Hasson**, *Senior Lecturer*, University of Ulster; **Barbara Cochrane**, *Director Medical & Care Services*; **Sue Foster**, *Lecturer*; **Helen Chambers**, *Director of Clinical Services*, Northern Ireland Hospice.

Background

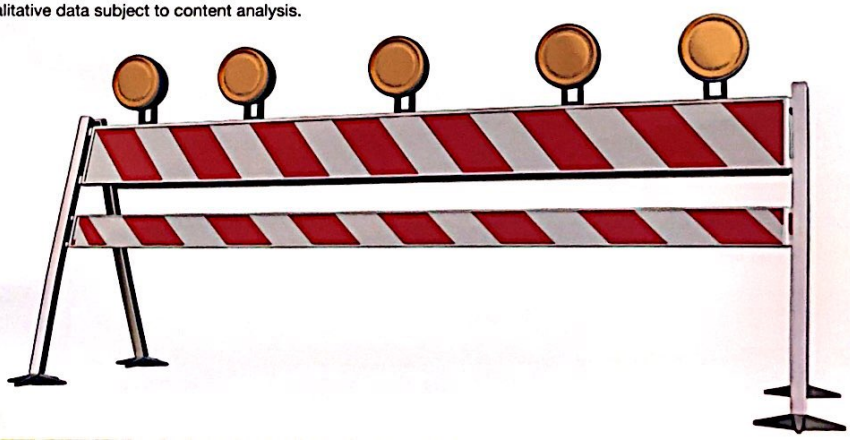
The effective and efficient delivery of palliative care is the responsibility of every health and social care professional. But, in reality unmet palliative care needs have been widely reported for malignant and non-malignant conditions, including Parkinson's Disease (PD). What are the barriers to translation of palliative care from terminal, cancer to supportive care for all?

Aims

- To explore the health and social care provider perspectives into Palliative Care barriers and facilitators for people with advanced PD.
- To identify how the quality of care at the end of life can be enhanced.

Methods

- Access to this sample was gained via Medical and Nursing Directors and Management of the Parkinson's Disease Society;
- Focus groups and interviews with health care professionals representing acute, specialist, community and primary care;
- Interview scheduled based on the literature and expert opinion;
- Full ethical approval obtained;
- Qualitative data subject to content analysis.



Sample Characteristics

- A total of 111 staff took part in the study (NHS = 39, Non-NHS= 72) .
- Over half (n=62, 55%) worked in the area of palliative care.

Personal barriers

Differing understanding of PD and the principles of palliative care among different professionals. Lack of recognition and understanding of the breadth of care provided within the palliative care framework. Palliative care is viewed in the medical model, largely as symptom control.

Organisational barriers

- Few received palliative care.
- Palliative care viewed as specialist area;
- Lack of referral triggers;
- Lack of integration.

Relational barriers

- Public perception that hospice is viewed as "cancer" and "end-of-life" care.
- Health professionals unwilling to broach topic of palliative care to patients and carers: negative perceptions.
- Specialist, generalist and AHPs working in isolation with little linkage between the systems resulting in limited input in palliative care;
- A lack of education and training in palliative care.

Compartmentalisation

- Results imply low resources and staffing levels impede the provision of an equitable and high quality palliative care service.
- Prioritisation for malignant conditions than for non malignant conditions.
- Perception that increasing referrals would result in Hospice inability to cope with increasing demand.

Facilitators

- Recognition of palliative care needs and
- the value of palliative care.
- Establishment of a key co-ordinating post to ensure needs are responded to in an timely and efficient manner.
- Emphasis on multi-disclipinary working
- Education and training on PD should be arranged for health and social care professionals.

Conclusion

Whilst professionals saw benefits, the meaning, timing and introduction of palliative care into the disease trajectory was unclear. Barriers to translation were related to personal, relational, compartmentalisational and organisational issues. There are clear needs for health and social professionals to examine their perceptions of palliative care and to consider promoting it to patients at an earlier stage, when it could make a positive difference in patients' lives.

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